



Alexithymia in children with cancer and their siblings

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ABSTRACT

Objective: The purpose of this study was to examine the levels of alexithymia in children with cancer, in siblings of children with cancer, and in healthy controls.

Method: In order to compare the groups the Alexithymia Questionnaire for Children was used. The study group consisted of 97 children with cancer, 95 siblings, and 151 healthy controls.

Results: The highest level of alexithymia was reported by children diagnosed with cancer, followed by their siblings. Healthy controls reported the lowest level of alexithymia. No gender differences were observed. The intensity of cancer was a significant predictor of the alexithymia score, with patients with the most severe cancers reporting the highest levels of alexithymia. No differences were found between the patients with moderately severe and least severe cancers.

Conclusions: Not only children with cancer, but also their siblings show significantly more alexithymia than their healthy counterparts. Professionals should aim at preventing or reducing the psychological problems in both patients and their siblings.

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Introduction

Childhood cancer is the leading cause of death caused by disease in humans under the age of 15. Yet, the estimated rate of 5-year survival of all childhood cancer patients is approximately 70 to 80% [1,2]. Because of the psychological stress caused by their cancer and its treatment, these children can experience many negative psychological side-effects, such as posttraumatic stress symptoms [3] or alexithymia [4,5]. Alexithymia is an inability to identify and communicate one's own emotion experiences. Primary alexithymia refers to a personality disorder, but secondary alexithymia emerges as a reaction to severe and prolonged stress, as in the case of a medical illness [5]. Both types of alexithymia in turn contribute to the development of various internalizing symptoms such as depression and anxiety [6]. Consequently, childhood cancer patients are at higher risk of long-term psychosocial and academic problems than their peers.

Although increasingly more attention is given to the psychosocial functioning of children with cancer, other family members also suffer psychologically [7]. Siblings, especially, are often overlooked, whereas the illness of their brother or sister negatively affects them, too [8]. Siblings of childhood cancer patients experience significantly more psychosocial distress and show more adjustment and behavioral problems than healthy controls [9]. Woodgate [10] interviewed siblings of children with cancer and reported – among other problems –

an “enduring sadness”. Nevertheless, Aldelfer and colleagues [8] note that most studies in this area still show methodological limitations (e.g., small sample sizes or quantitative data), so more research is needed.

As childhood cancer can be extremely disruptive of daily family life and emotional well-being, it is important to examine emotional functioning not only in children with cancer, but also in their siblings, so that professionals can give adaptive support, resulting in long-lasting psychological adjustment and better coping skills in both groups. The objective of the study presented here was to examine alexithymia in childhood cancer patients, their siblings, and healthy control children. We expected children with cancer and children who have a brother or sister with cancer to show more emotional problems than healthy controls, as measured by an alexithymia questionnaire developed especially for children [11]. We also expected the intensity of the disease to correlate positively with the level of alexithymia in children with cancer.

Method

Participants and procedure

The total group of participants was made up of 343 Indian children and young adolescents (166 girls and 177 boys), with a mean age of 13 years in all three groups (age range 9 to 18 years old). The group consisted of 97 children (44 girls and 53 boys) diagnosed with cancer, attending an outpatient's clinic at the Bai Jerbai Wadia Hospital for children (Mumbai, India), 95 siblings (46 girls and 49 boys) and 151

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controls (76 girls and 75 boys). Parental consent was obtained for all participants. The questionnaire was filled out by the children at the hospital, while waiting with their parents for the results of their blood test or a consult with their doctor. Siblings and parents were also approached when they visited the hospital and asked to participate. Approval for the study was granted by the head of the division of Pediatric Hematology, Oncology, and Immunology. The healthy controls were recruited from a primary school in Mumbai. Parental and school authority permission was obtained prior to the study.

Materials

Consistent with the original adult questionnaire for alexithymia (TAS-20) [12], the *Alexithymia Questionnaire for children* [11] consisted of 20 items, representing three factors: Difficulty Identifying Feelings (DIF, 7 items), Difficulty Describing Feelings (DDF, 5 items), and Externally-Oriented Thinking (EOT, 8 items). For the translation of the questionnaire into Hindi, we followed the procedure that was first introduced by Brislin in 1986 [13]. The translation of the Alexithymia questionnaire into Hindi was done by a native Hindi speaker. Another native Hindi speaker, who was also fluent in English, back-translated the Hindi version into English. This version was then compared with the original questionnaire by a native English speaker.

Respondents were asked to rate the degree to which each item applied to them on a 3-point scale (0 = *not true*, 1 = *true to some extent*, 2 = *true*). A Principal Component Analysis (PCA) on the 20 items, with the factor count limited to the three factors, showed that most items from the first two factors were clustered together, whereas the items belonging to the third factor failed to load sufficiently. Since in many previous studies [11] the third factor had also showed poor psychometric properties and predictive validity, it was omitted from further analyses. The two remaining factors, DIF and DDF, were taken together. A PCA on the remaining 12 items, with the factor count limited to one single factor did indeed show that all items loaded higher than .40 on this factor, except for item 4, which had a loading of .23. However, this item was not omitted from the questionnaire, because the combined scale still showed good internal consistency with all 12 items included (Cronbach's Alpha .78; mean inter-item correlation .23). This is consistent with the literature on this questionnaire [14]. The 1-factor solution explained 31% of the variance. The mean score over these 12 items is used in this study.

Results

The differences between the three groups on the Alexithymia measure were assessed by a 3 (Group: Children with cancer, Siblings, and Controls) × 2 (Gender) analysis of variance. The level of significance used in this study was <.05 and Bonferroni correction was applied for the post-hoc *t*-tests. The analysis showed a main effect for Group ($F(2, 337) = 27.91, p < .001$). No effect for Gender appeared significant. Post-hoc *t*-tests showed that children with cancer scored higher levels of alexithymia than their siblings and controls ($p < .008$; and $p < .001$ respectively). Additionally, the siblings scored higher than the controls ($p < .000$; $M = 1.29, SD = 0.41$; $M = 1.17, SD = 0.24$; and $M = 0.90, SD = .50$ respectively).

The doctor who treated the children with cancer rated the severity of their illness as 'least severe' (29 children), 'moderately severe' (58 children), and 'very severe' (10 children). An analysis of variance showed a difference between the three groups on the Alexithymia measure ($F(2, 96) = 3.23, p < .044$). Post-hoc *t*-tests showed the highest alexithymia score for the most severe group ($M = 1.59, SD = .37, p < .008$ and $p < .010$ respectively), and no difference between the moderately severe and least severe groups ($M = 1.25, SD = .43$; $M = 1.27, SD = .34$ respectively, $p < .778$).

Discussion

Our findings confirm previous studies: children with cancer report more alexithymia than their healthy peers [4], and this affected especially the group with the most severe intensity of cancer. Additionally, our study is the first to systematically show that children who have a sibling with cancer also report more alexithymic features, although still less than the group of cancer patients. Therefore, it is important

to examine emotional functioning not only in children with cancer, but also in their siblings, so that professionals can give more adaptive support, for example by informing parents, and prevent or reduce long-lasting psychological problems in both groups. Future studies could examine this topic in more detail and for example include the perceived level of stress as a possible mediator in the relation between alexithymia and cancer [15].

Although the validity of self-report questionnaires in children is frequently questioned, it has been argued that internal states, such as emotions or reflections upon these emotions, are best known to children themselves, because it is only they who have direct access to their own emotion experience. Several studies have indeed confirmed that it is most appropriate to ask the child itself, which is especially true for internalizing problems [16,17]. This view is further supported by the fact that the internal consistency of the self-report questionnaire in our study was high. Note however that in line with previous studies [14], the scale 'Externally Oriented Thinking' was omitted from the Alexithymia scale, due to poor psychometric properties.

Additionally, we would like to point out that this study was based on a single measure for emotional functioning, the alexithymia questionnaire for children and that the outcomes should be interpreted as tentative. Another limitation was the fact that control children were tested in school, whereas the children with cancer and the siblings were tested under more stressful conditions in the hospital. These different circumstances might have affected the outcomes. Future studies should use a multi-method approach, also including other indices for emotional functioning and, when possible equalize the test-setting for all groups. In conclusion, we hope that by examining this topic we have created more awareness about alexithymia in childhood cancer patients and their siblings, and that these findings will help design additional research. In this way we can further improve our understanding on this topic and implement better counseling trajectories for these children in the future.

Conflicts of interest statement

None declared.

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